

**Stronger Together** 

September 9, 2014

The Honorable Joe Bolkcom Interim Cannabidiol Implementation Study Committee State Capitol Bldg, Room 116 Des Moines, Iowa 50319 The Honorable Walt Rogers Interim Cannabidiol Implementation Study Committee State Capitol Bldg, Room 116 Des Moines, Iowa 50319

Dear Co-Chairs Bolkcom and Rogers:

On behalf of the Epilepsy Foundation of North/Central Illinois, Iowa, and Nebraska, we welcome the legislatures' interest in creating safe, legal access to cannabidiol (CBD) as a treatment option for Iowa residents living with intractable epilepsy, but are concerned that current state law does not provide meaningful access to CBD. SF 2630 and the proposed rule for implementing the state's medical cannabis program allow individuals with intractable epilepsy to use CBD oil and lay out a process for applying for, obtaining, and maintaining a registration card. But the question of where the CBD oil will come from remains unanswered, because the law does not allow for growing, processing, and dispensing of CBD. Families would have to break the law or take their chances with unregulated products marketed as CBD, both risky options that were not envisioned by legislators when they passed SF 2630 earlier this year.

The Epilepsy Foundation of North/Central Illinois, Iowa, and Nebraska represents Iowa residents living with epilepsy and seizures, and fosters the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. There is no "one size fits all" treatment option and about one third of the more than 2.8 million people living with epilepsy experience uncontrolled or intractable seizures, despite available treatments. Some of these people may be helped by surgery or other non-drug treatments, but for many, no answers have been found yet.

We are committed to supporting physician directed care and to exploring and advocating for all potential treatment options for epilepsy, including CBD oil and medical cannabis. People with uncontrolled seizures live with the continual risk of serious injuries and loss of life. This is why many individuals who have run out of options turn to CBD. If a patient and their healthcare professionals feel that the potential benefits of medical cannabis for uncontrolled epilepsy outweigh the risks, then families need to have that legal option. Nothing should stand in the way of patients gaining access to this potentially lifesaving treatment.

The state's current medical cannabis program does not allow for growing, processing, and dispensing cannabis and products derived from the cannabis plant. This means that families seeking this treatment option would have to travel out of state to obtain CBD oil, and break federal laws by bringing it across multiple state lines. Although 34 states have passed some

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form of medical cannabis legislation, none except Oregon allow out of state residents to legally access CBD oil, and even in Oregon the patient must obtain a registration card and a recommendation from a physician licensed in Oregon. Illinois and Minnesota recently passed medical cannabis legislation that will allow for cultivation and distribution by state approved entities. These states, and many others throughout the country, have recognized that providing safe and comprehensive access to this treatment option requires the ability to cultivate medical cannabis and process and dispense CBD under state supervision.

It is very difficult and risky for families to obtain CBD oil out of state, and many will look for in-state options. Unfortunately, since there is no legal pathway for growing, processing and dispensing cannabis and CBD oil, these same families may seek products marketed as CBD oil that may turn out to be unsafe preparations with little or no CBD oil or medical benefit. Some families may seek to be part of clinical trials for drugs derived from medical cannabis, but clinical trials have limitations on the numbers and types of patients they can enroll, making it hard or impossible for families to enroll in trials. For many Iowa families, breaking the law, purchasing unregulated products marketed as CBD, and clinical trials are not an option. This is why we call on the state legislature to expand the medical cannabis program to include state oversight of legal growth, processing, and dispensing of cannabis and CBD oil. The state can play a critical role in ensuring that access to CBD is safe and reliable. We urge you to act so that families don't fall victims to unscrupulous individuals selling unsafe products marketed as CBD, or feel the need to consider breaking federal and state laws by traveling across state lines to obtain CBD oil in states where only residents are legally allowed access to this treatment.

The Epilepsy Foundation of North/Central Illinois, Iowa, and Nebraska, thanks you for your careful consideration of our concerns with the current medical cannabis program. We look forward to working with the legislature to ensure safe, reliable, and legal access for Iowa residents living with epilepsy and uncontrolled seizures. Please do not hesitate to contact Angela Ostrom, COO & Vice President Public Policy at 301-918-3766 or aostrom@efa.org, with any questions or concerns.

Sincerely,

Roxanne Cogil

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Director of Iowa Epilepsy Services

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